

## Data Management Sessions: EBMT 2013 REVIEW

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The 12th Meeting of the Data Management Group held at the EBMT Annual Meeting in London this year proved once again to be an enjoyable event.

There was a record attendance and around **184** Data Managers from **29** countries at the event from a variety of European countries and from as far afield as Korea, China & Brazil.

The Educational sessions included: Chimerism; HLA mismatches; improved Data Quality; EBMT transplant activity survey; Autoimmune and CLL Med B; Complications; Clinical trials - and many others. We are, as always, extremely grateful to all of the speakers who make such an effort to prepare interesting and informative presentations - so once again, thank you - to all of them for the hard work which they put into their presentations: Bobby Gaspar, Maria Calaminici, Steven Marsh, Steffie van der Werf, Emma Das-Gupta, Liesbeth de Wreede, Helen Baldomero, Carmen Ruiz de Elvira, Johannes Schetelig, Jacob Passweg, Alicia Rovio, John Murray, Zora Marjanovich, Liz Clark.

Slides from the educational sessions are available in the [slide bank](#) on ebmt.org. (Scroll down to Data Management section and click on the speaker's name to view). Please do have a look at these even if you did not attend the conference as they are very informative and can be useful educational sources.

The EBMT Registry Database (ProMISe) training courses were also well attended. Special thanks to all of the presenters and colleagues who helped with all of these sessions - Leila, Arnaud, Marie T, Lucas, Stephanie, Tunde, Richard, Emmanuelle, Nicole, Helga, Franziska, Hervé, Jennifer, Anja, Marlies, Shelley, Asterios, Keiren, Julia, Jude, Beate and especially Henk Jan.

In addition, we saw the official presentation and demonstration by Remedy Informatics, provider of the new EBMT Registry System. This is where many of us were able to find out more and see for the first time how the new system will look before it goes live in December 2013. The current status of the project is included overleaf.

**Future presentations:** We are always pleased to hear from you regarding suggestions for topics for the Data Management Education programme, please email your ideas to: [registryhelpdesk@ebmt.org](mailto:registryhelpdesk@ebmt.org). Similarly, please contact us if you feel you could undertake a presentation sharing examples of interesting or innovative aspects of your Data Management work.

**Thank you** to all the Data Managers who completed the feedback forms - these are very important to help us plan future sessions. A [copy of the report](#) from the feedback is available on our website

Finally - **SAVE THE DATE** - We really hope to see as many of our Data Managers again next year at the [EBMT 2014](#) in Milan (30th March to 2nd April) - where we will be celebrating 40 years of EBMT!

Three Data Management and two Statistics posters were displayed and there was a Data Management Reception which was enjoyed by many Data Managers and their colleagues.



## Update on the Registry Upgrade Project



The EBMT is dedicating significant efforts to improve this invaluable tool and its implementation relies on funding from different sources: transplant centres, corporate members, National & Donor Registries

### We need your help

We are very grateful for your support. If your centre has not yet donated, it's easy to donate at <http://registryfunding.ebmt.org/>

Please click [here](#) to download a more in-depth comprehensive presentation of the Registry Upgrade Project.

Throughout the year we will be working with our new technology partner, Remedy Informatics. Following the overview presentation at EBMT 2013, we would like to update you on the current status of the project: Final requirements have been completed and approved. The platform has already been upgraded so that users will be able to work directly through their internet browser, without downloading any additional tools. Configuration is still proceeding, to be accompanied by data migration and testing. We would very much appreciate your help with the data quality checks below to assist with the data migration process. Tentatively, the plan is to train EBMT and National Registry staff later in the year. Following this we will roll out the training to Centre users. The dates are still to be announced. We anticipate to have a clearer schedule by the end of August.

## Data Quality Checks

In relation to the Registry Upgrade mentioned above, this is a very good opportunity for Centres to look again at their data and to check the Data Quality before it is transferred into the new system. Some records may not be transferable if the data is not coherently recorded.

### Data Quality reports

Many national registries are in regular contact with centres regarding missing items, data discrepancies and follow up updates. However not all centres have this contact, so this appeal is to those centres in particular.

For users who currently have access to ProMISe, a good place to start is to run the Data Quality Reports which are available to all centres. (Even if you do not use ProMISe to submit data, you can still apply for access in order to check your centre's data registration status and quality)

These reports can help you to identify some key issues such as invalid data, missing data, duplicate information, incorrect diagnosis, error messages and conflicting information. A guide detailing how to run these reports is available in the Data Management section of our web site: [Guide to producing Data Quality Reports in the EBMT Registry Database Using ProMISe](#)

The reports are straightforward to run – they make it easy to see where data is missing or wrongly entered and then you will have the opportunity to correct the errors.

If you are sending any data by mail to the [Registry Office, London](#), here is a reminder of our new address. Phone/fax/email remains the same

### EBMT Registry

4th Floor  
Tabard House  
Guy's Hospital  
Great Maze Pond  
London SE1 9RT, UK

Visitors/couriers should use the following address:  
4<sup>th</sup> Floor, Tabard House, Talbot Yard, London SE1 1YP

## Follow Up due

We would also like to remind you of the importance of regular follow up reporting. This is a crucial contribution for the analysis of outcome data. In November 2012, the Registry Office sent follow up reminders to all centres containing patients without a follow up report for at least 5 years.

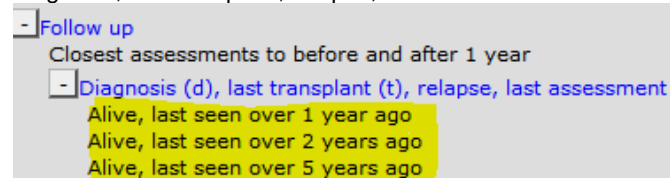
You can also run a pre-programmed report in ProMISe to generate a list of your patients last seen more than one year ago, more than 2 years ago, or more than 5 years ago. To run these, follow steps 1-4a in the above guide but select from these report titles:



In tab [Report] – [Specify]

Stored Report Specifications:

DATA – COLUMNAR – ADVANCED – Project – Follow Up – Diagnosis, last transplant, relapse, last assessment:



## Missing Data checks

In addition, it might be helpful to run the **Med-A Merge** report in order to check for missing data. The report can produce an Excel file of all Med-A (plus follow up) with any relevant items missing. Please go to this web page

<http://www.ebmt.org/Contents/Data-Management/Dataretrieval/Pages/Data-retrieval.aspx>

And scroll down to 'Data Processing after Download' – MED-A paper form merging.

If you would like any help, have any questions or experience any difficulties with running these reports please contact us:

[registryhelpdesk@ebmt.org](mailto:registryhelpdesk@ebmt.org). We will be very happy to help you!